



Strategies of Mothers in Life Management Along with a Child with Congenital Heart Disease: Valuable Experience of Iranian Mothers

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Authors' contributions

This work was carried out in collaboration between all authors. Authors MN and SS designed the study, wrote the protocol and wrote the first draft of the manuscript, managed the literature searches, analyses of the study performed the spectroscopy analysis. Author TM managed the experimental process and author AR identified the species of plant. All authors read and approved the final manuscript.

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ABSTRACT

Mothers of children with congenital heart disease used a variety of ways for caring. Mothers, caring approach is dependent on several factors: Culture, mentality and attitude, available resources.

Aim: This study investigates how Iranian mothers of children with congenital heart disease manage care according to their context.

Study Design: A qualitative content analysis was used to obtain rich data.

Place and Duration of Study: The study was conducted in Kerman, Iran from 2014 till 2016, among mothers of children with CHD.

Methodology: The purposive sampling technique was used to select the participants. Participants were 17 mothers and 3 fathers of children with CHD and 3 heart surgery nurses, from two hospitals affiliated with the Kerman University of Medical Sciences. Twenty five semi-structured interviews were constructed. Data were analyzed using qualitative content analysis. Constant comparative method was used for data analysis.

Results: The analyzed data were made into four main themes and nine sub-themes. The main themes are Wise to wait (Patient care, enduring difficulties and sufferings), improving living conditions (Imposing situations' pressure on self, gradually coping with child's disease, Providing appropriate conditions for the child), acceptance of limitations of sick child (acceptance of the conditions of child by mother, acceptance of the limitations by the child), empowering (Empowerment of the child, self-empowerment) appeared by analyzing data. The results of this study may help health care professionals in understanding strategies of mother's care of children with congenital heart disease in Iran.

Keywords: Congenital heart disease; children; parents; care; qualitative study.

1. INTRODUCTION

Congenital heart disorders were recognized as complex diseases of the cardiovascular system in 2006 which are caused by poor function of embryonic heart structure [1]. From 150 million births annually around the world, 1.35 million people are born with CHD [2]. There is no proof to indicate the lower prevalence of this category of diseases in developed countries compared to developing countries [2] and the high prevalence of this group of congenital diseases are among major health issues in the world today [3]. In a study conducted in 2008 in Iran, the prevalence rate has been estimated to be 12.3 per 1000 [4]. The number of children with CHD has increased from less than 1 in 1,000 births in 1930 to 9 in 1,000 births in recent years [2]. Advanced knowledge in the field of diagnostic and screening methods [3] has led to an increased number of patients. Advanced medical practices and technological advances have led to increased longevity of this group of patients. This highlights the importance of detailed planning for health and care in order to improve the management of living conditions of this group of children.

[4,5] parents of these children face problems, such as lack of physical vigor [6], early fatigue, exertional dyspnea, growth defects, infection, developmental delay, dental problems and heart failure symptoms [4] and delayed developmental milestones [7] and managing all of these problems causes stress and anxiety in parents [8] and imposes heavy financial, physical and mental burden on them [9].

Despite high levels of stress and anxiety associated with the disease in children [9]

Parents must seek proper care for their sick child. Parents require special care programs related to their child's disease for performing tasks which meets all the needs of children in different age categories [10]. This disease is not the end of life for the patient, but it is rather considered as chronic disease [11]. Parents of these children are always struggling in order to meet multiple pharmaceutical, social, emotional and functional needs [5].

Parents solve many of their problems during the occurrence of these diseases and cope with a number of other problems [12] but they have fear of disease's unknown future, prognosis and treatment outcome [13].

Besides these issues, the wrong understanding of the methods of managing sick children and the lack of information and awareness of the disease and treatment process reduces the implementation of the implementation of optimal and effective care by parents and leads to a high level of anxiety in parents, especially in mothers [14]. Mothers' anxieties are related to the future life of children and the fear of losing the child instead of severity and type of disease [15].

But this anxiety leads to decreased quality of life of mothers [16] and thus compromises the quality of care function in them as the main child care providers which makes the implementation of training and support for this group of mothers a necessity. Mothers have to perform the hard task of taking care of children in physical, emotional and social dimensions, in addition to handling family issues and other problems of life. Family situations have an impact on the mother's quality of care [17]. In recent years, experts who provide optimal care have found that family members

who care for a sick child can have a very effective role in the child's health with his/her support [10] and this type of care is usually affected by values, beliefs, culture, idea, and expectations of the family [18]. A large number of parents change their attitudes towards life, death, objectives, expectations and wishes at the time of the child's disease [19]. Parents are also concerned about the effect of disease on issues such as growth and development, function and sense of well-being of children [15]. All of these issues affect the quality of care for their sick child and the lack of peace of mind experienced by the families does not affect their ability to provide optimal care to children. Parents of these children face various problems such as socialization of their sick child. They are mostly trying to tell their child that he/she can have a normal life like normal children [20]. While, correct behavior from parents and having realistic expectations can lead to accurate and consistent care for the child and have favorable results for him/her and the family [19].

In the treatment of this group of children, there should be enough attention not only to the child as a patient but to the whole family especially their parents [21]. This is critically needed due to the need for full time caring of mothers of sick children and the psychological and social effects the disease has on them [2]. Emotional, social and psychological support for them is inevitable. Each mother tries to provide the best possible form of caring for her child using a particular method of caring. Caring methods used by mothers are affected by their personal beliefs about the disease of the child, the structure of family, racial factors, cultural beliefs, and socioeconomic status.

Despite awareness about the importance of the above factors, there is not enough information for understanding cultural variables affecting caring method of this group of mothers and their caring methods. On the way forward, society needs to meet the needs of education. Among the tasks of nurses is to develop educational ways to reduce anxiety, depression and life skills in order to take better care of children [22]. Mothers of these children usually try to use a method of management to handle their caring problems and the special conditions of their child based on their mentality, education, specific culture, and the amount of resources available. A deep understanding of a child disease management program and strategies for taking care of the children can help nurses to complete the

identification of the needs of these children and their mothers and provide nurses with the ability to help families, especially mothers who can gain more awareness and understanding. Mothers will experience stronger support after appropriate solutions are provided by nurses. This will make them more likely to be involved in better and faster management as they achieve enough knowledge, information and training. Consequently, they will have more accurate, effective care for their child.

In addition to this, a deep understanding of the strategies that they themselves have developed can also be used to improve the lives of other sick children and their mothers, while making a good impression on them. This can help mothers to take proper care of their children. Thus, we used a qualitative study to deeply explore care strategies used by mothers of children with congenital heart disease in Iran. This qualitative study was undertaken according to Iranian culture, and special laws were followed based on the experience of this group in order to achieve evidence-based comprehensive responses.

2. MATERIALS AND METHODS

The current study is part of a larger one related to a doctoral dissertation. It was done using a qualitative approach and content analysis for identifying how the mothers of children with congenital heart disease care for their children. Qualitative content analysis is an appropriate method to obtain variable and reliable results from textual data. This method is used to create new knowledge and ideas, and provide facts and guidelines, aiming to condense a broadly described phenomenon, with achievements of concepts or descriptive classes of the phenomenon [23].

2.1 Study Design and Participants

This study was conducted in Kerman, Iran from June 2014 to February 2016. The city of Kerman is located in the southeastern part of Iran in an area with cultural diversity and mixed ethnicity. The extent of Kerman province, the dispersion of its population, and the high prevalence of congenital heart disease in the south of this province in conjunction with deficiencies in healthcare in this area and the long distance trips taken by parents and sick children to visit doctors are problems which mothers must face. In this study, participants included mothers of children suffering from congenital heart disease seeking

treatment in the specialized heart centers of two educational hospitals affiliated with Kerman University of Medical Sciences, to which patients with heart disease, especially those from the south of the province, usually refer.

2.2 Participants and Sampling Method

Purposive sampling was used to select participants for this study. The population comprised 17 mothers and 3 fathers of children with congenital heart disease admitted to hospitals affiliated with Kerman University of Medical Sciences, Iran and 3 nurses working in the ICU for patients of open heart surgery. Data collection was continued in theoretical sampling. In this regard, Interviews were conducted with fathers and nurses until saturation which occurred when a new category did not appear and until the existing categories were enriched.

These two governmental hospitals admit patients with all types of insurance.

The researchers attempted to observe maximum variations in terms of demographic characteristics (numbers of child, level education and economic) and type of heart disease. The researchers also attempted to interview knowledgeable mothers who could deliver broad insight into their responses to the study question. Inclusion criteria included the ability to speak the Persian language, the child's age being between 7 months and 14 years, diagnosis of child's disease at least 6 months prior to the study, and the participants' willingness to participate in this study. Exclusion criteria were cognitive impairment confirmed by a psychiatrist.

2.3 Data Collection

Data was collected through face-to-face, interviews conducted by a PhD student in nursing who was a research team member. Team members were 3 associate professors and a PhD student of nursing. Interview locations and times were agreed upon by both the interviewer and the interviewee. Written and verbal consent was obtained from each participant by the investigators.

First, the researcher clarified the study aims and explained its benefits to the participants. Then, based on the study's objectives, general questions were raised. Several examples are as follows: how do you care for your child? Please, explain one day of care your child? How do you

solve your problems? Based on each interviews analysis, We modified next questions.

Interviews were conducted either at the hospital or at the home of the researcher and lasted between 30 and 90 minutes with an average duration of 55 minutes.

2.4 Data Analysis

In the present study, content analysis was done according to the proposed method of Graneheim and Landman [15]. First, the first author listened to the recorded interviews 4-5 times. In the next step, the whole interview was typed word by word in a Microsoft word document. Interview was transcribed and regarded as a unit of analysis. Some texts were reviewed by the same interviewee and corrected if necessary. For better understanding, every finalized text was studied by one of the members of research team and the meaning units were extracted. The meaning units were categorized and summarized based on similarities and differences and the meaning codes were extracted. According to the degree of relatedness among meaning codes, they were classified into subcategories which represented the same subject. The assessment of interrelations among subcategories were done and the main concepts were extracted from them. At the end of each step, the findings were discussed among research group members. The final findings were discussed with the participants in a meeting and their final remarks were received. For including the classification data in the data analysis step, we used MAXQDA software.

2.5 Ethical Considerations

Ethical considerations were addressed before the study began. All participants completed written informed consent forms and were assured that their information would remain confidential. This study was approved by the Ethics Committee of Kerman University of Medical Sciences (ethical codes/324/93). Study purposes, confidentiality of data, and recording of interviews were clarified for the participants before their interviews, and their verbal agreements were obtained.

3. RESULTS

From 23 participants in the study, 17 were mothers of children with congenital heart disease, 3 were fathers and 3 were nurses of

cardiac surgical intensive care unit and two mothers were interviewed twice (A total of 25 interviews). Second interviews were conducted with two mothers to complete findings and answer some questions from the first interview.

The age range of participating mothers was 27-50 years (the average of 33.5 years). Interviewed mothers had children with congenital heart problems in different degrees and intensities and under treatment in different stages of disease who were treated at public health centers (due to lack of private centers for pediatric heart). Wise to wait, improving living conditions, acceptance of limitations of sick child, empowering classes appeared by analyzing data.

In this study, all mothers were at different hard stages of their child's disease from diagnosis to surgery period and then they were always looking for ways to be able to have a quality care for their sick child. They were using different resources available to achieve this goal. Although the lack of resources and the protection and care of child was a burden heavy for them but their efforts for better management of specific conditions were laudable. They were trying to bring the best care for their child by searching and using different ways and be able to provide more relaxation for their sick child in order to have better results from their caring.

3.1 Wise to Wait

Almost all the participants in this study have selected resistance procedure against problems caused by disease and the treatment of their child and were trying to endure the stresses they had due to the child's disease.

3.1.1 Patient care

In this regard, the mothers participating in this study patiently struggled to obtain optimal care for their sick child at all stages, and they endured many hardships during their child's disease.

Participant [4] expressed about caring patiently that: "I did not force my child to act quickly when I was breast feeding him because he did not have sucking power and his breaths were low. I had to do this process slowly or pull from his mouth and wait a while and feed him again" Participant [10] expressed: "it took a while before I brought my child to the hospital because of my financial situation. I was extremely worried but I could not do anything and I just waited. I saved money, did

not buy to save some money and bring him here. I always had hoped that I can bring him here. I endured a lot of difficulty. The fact that I could not bring him here was extremely hard for me".

3.1.2 Enduring difficulties and sufferings

All the mothers in the study pointed out visible and invisible difficulties that they faced in this period and the fact that they endured the burden of these problems. In a way that participant [1] expressed:" I locked myself for at least 6 months so that my child do not be at risk for disease. I was looking for anyone who is sick even in small parties. I did not let anyone hug or kiss my child. I was extremely observant because the doctors always said that cardiac children are much weaker than the other children. I endured a lot of difficulty so that my child does not get sick".

Participant [6] expressed:" I endured a lot of difficulties last year because my child had unclear situation. I did not what I should have done when I was at work. He woke up so hard in the morning when I took him to kindergarten. He would cry and be annoyed. I was an extremely difficult period. I really did not know what to do.

There was a difficulty everywhere I looked. I never want to it to come back".

3.2 Improving Living Conditions

Improving living conditions in this study included sub-themes of imposing situations' pressure on self, gradually coping with child's disease and changing the routine process of life.

3.2.1 Imposing situations' pressure on self

Mothers experienced difficult and different situations based on the illness of their child. They had to endure some of the problems in this especial situation of illness. In fact, they had no other way other than accepting child's disease, him/her being abnormal and his/her abilities and accept restrictions. The majority of mothers had no other way with the exception of enduring some issues and problems in this study and endured the situation because of not being able to perform other solutions or not having any other solution.

Participant [13] expressed:" when I went to visit the doctor of my son, I asked him what should I do? I usually listened to everything he said. I had

no other choice. I had to and I preferred to listen to the doctor's words".

Participant [9] expressed:" his father cannot bear to see the child, he is extremely afraid. He is afraid that something would happen to the child during the operation and always call and asks about his condition but he has never come here. I had no other option, I had to bring the child for his operation otherwise I would have lost my child".

Participant [6] expressed:" I took him to kindergarten for several mornings and he had an aunt there who said I do not give drugs to kids. I even went to Social Welfare so that they give the child's drugs to him but they did not do it. I had to wake my child up early in the morning and give him his drugs and then take him to kindergarten but normally I never woke him up even if I had to do a necessary work, I would cancel it if my child was asleep and I did not do that work".

Participant [7] expressed:" I only rested for 2 hours a day in early stages of my child's disease due to disease conditions and his bad conditions. You may not believe me but I only had this type of rest for two years. I could not do this anymore".

Participant [2] expressed:" I always cooked healthy and nutritious foods for him. I had to cook them for him. This little amount that he ate was so valuable for me. I had to cook fresh food. I believed it to be my responsibility. I forced myself to cook fresh food for him every day and give it to him".

3.2.2 Gradually coping with child's disease

A large number of participants in this study did not believe the illness of their child and tried to escape from the created situation by not referring or following up the conditions and changing the doctor with hopes of diagnosis of other illnesses or lack of illness by the new doctor. But with the passage of time from diagnosis they gradually coped with existing conditions and mothers gradually became calm. Not only they coped with this conditions, but they also tried to lead their ill child to directions where they can cope with the conditions as well.

In this regard, Participant [11] expressed:" at first, I did not believe when they told me that my child is sick. I struggled a lot because he was too

weak and had a low weight and screamed a lot. He had a lot of problems but I gradually coped with these difficult conditions. Now I feel a lot better than early stages".

Participant [5] expressed:" I felt really bad at first but I gradually found out that if I want to do anything for my child I have to cope with the conditions and I have to think about healing my child. I have to think about things I should do for her in order to heal faster. Then time gradually passed and conditions got a little better".

2.2.3 Providing appropriate conditions for the child

Here mother tried to adjust her life in a way so that she can spend the most amount of time with her child based on sickness conditions of the child and his/her need for full-time care. She even gave up her education and career in this path. In a way that participant [6] expressed:" I was always afraid that something would happen for my child in kindergarten. Finally, after lots of thinking, I decided to have consultation with his doctor. The doctor wrote a letter for my work which indicated that the child cannot be kept in the kindergarten and is suffering due to multiple difficulties and extreme psychological dependence and I took unpaid leave for three years.

Also participant [5] expressed:" in could no longer work with sickness of this child and because I worked in a private company, I could not take time off and I was unemployed".

Participant [3] expressed:" I gave up my education because I saw that I cannot take care of my child and go to school because he was not a normal child".

3.3 Accepting the Created Situation

Accepting the created situation in this study included two sub-themes of acceptance of the conditions of child by mother and acceptance of the limitations by the child.

3.3.1 Acceptance of the conditions of child by mother

The level of accepting the disease and disabilities and limitations of living with a sick child takes place in this group of mothers after emotional ups and downs of the mothers by spending a long time. After spending a long time, mother not only tries to accept the disease and

disabilities of her child but also tries in any way she can to help the child cope with created issues.

Participant [4] expressed: "my child should never try running and football. Right now, if we walk for a long distance, he says that I am tired and take a taxi and I also accept that he is not a normal child and he is impotent and cannot have activity as much as other children at this age. He is sick and I must create conditions where he does not get tired".

Participant [4] expressed: "even come home early some nights that we go to wedding or even me and my child do not go there. He is extremely annoyed, I do not want him to have stress. He is not a normal child. He needs more care. Sometimes he gets extremely nervous or very upset over a small issue. His lips turn to black. Sometimes even his nails turn to black too".

3.3.2 Accepting the limitations of child

Sick children usually became aware of their limitations from 5-6 years old and when they faced shortness of breath or lack of physical vigor. They would manage themselves and would stop that activity and would start to do other things. They had a cooperation with their mother in this regard especially mothers who always talked to their child in this regard and provided the necessary training to them.

Participant [10] expressed: "my child cannot run a lot or have a lot of activities, he has shortness of breath or when we go to the park, he does not run a lot or does not use skating rink a lot. Then he sits. He completely understands that he cannot run anymore and he sits or says Mom I'm tired".

Participant [2] expressed: "when my child goes out to play with other children, he brings them home and starts to play Mensch or computer games with them instead of joining them and running with them. He knows that he will feel bad if he starts running. He more often convinces them to play games he is able to do".

3.4 Empowerment

Empowerment in this study included empowerment of the child in order to perform self-related caring activities and usage of resources and possibilities by mother for empowerment of herself.

3.4.1 Empowerment of the child

Children usually became aware of their limitations from 5-6 years old and the child would manage the situation when he/she faces problems such as shortness of breath or lack of physical vigor and would stop that activity any way he/she could and would try something else using matters which mother have taught him/her and mental preparation which are created in him/her. Children had more cooperation with mothers who always talked to their child about methods of self-protection and provided necessary trainings to them.

Participant [13] expressed: "my child always knows when he should rest when he is running or which activities will make him feel bad. I have always trained him. I tell him not to do some activities. I myself provide information to him. I always say to him let's search together. I always talk to him and remind him of his care tips".

Participant [14] expressed: "I have always told him which activities would be bad for him using different methods from the age of 4-5 and that he should be careful. I trained him according to his age then and I do this now but now he can search for things related to his disease or problems which have shaped up in his mind because he has gotten older and he always searches for the answers of questions in the field of his disease".

3.4.2 Self-empowerment

Mothers in this study can try for empowerment of themselves using resources and facilities which exist for caring of the child. They tried to provide useful and effective cares using consultation with the people of knowledge (nurses, doctors), the application of inventiveness, obtaining information from intelligence sources (books, internet) and using their own or others' experiences.

Participant [6] expressed: "My husband and I visited Psychologist a few times before because we felt we should have proper behavior toward the child. I asked my questions from Psychologist about what should I do with this child and how should I behave so that he does not become capricious and also will not have stress. I paid attention to all of the recommendations of the psychologist and carried out all of them.

Participant [4] expressed:” I always consulted with nurses and I asked them the proper method of giving medicine to my child and their behavior with the child was exemplary for me”.

Participant [6] expressed about using ingenuity and creativity in care:” If I see that he really likes 2 things, I would say to him, listen you have done that good thing today and I will give you this because of that good thing you did. This way, he is encouraged to do good things”.

Participant [5] expressed:” I would hug her when she ran a lot or did a lot of activities. I always explained to her that running a lot is bad for you, you would feel bad, and I would make her up to look pretty. I would always talk to her and convince her that she should not do some activities”.

Mothers in this study, used newspapers, books or the Internet based on their education level in order to manage the disease of their child.

For example, Participant [4] expressed:” I try to study books for any questions that I would have whether it is mentally or it is about drugs’ complications or the disease of my child form books that I have or even from the internet. I borrow different books about the disease of my daughter form my work and I read them”.

Participant [20] expressed:” I studied a lot, I would read book in order to find out what I should do with him. I read books about the age of my child and got some information in the internet. I was very careful with his nutrition. I would cook nutritious foods with turkey meat and ...”.

Participant [13] expressed about using their own and others experiences:” because I myself had experienced Teucium polium and was good for me, I have it to him to”.

Participant [2] expressed in this regard:” when my child was hospitalized, I always went to other rooms of the hospital to see if my child has worst conditions or other kids. I met other mothers there. Talking to them somewhat made me calm and at the same time I learned a lot of things from them. I would use their help if I had any question.

Participant [5] expressed:” me and some other mothers were in waiting room those two days that my child was in ECU. Those days we talked about food that we should give more to our children for them to have speedy recovery. They

told me some of the side effects of drugs which occurred for their children or even taught me some of the caring notes”.

Participant [13] expressed:” I have met some other mothers whom their child has similar disease as my child and we are in contact with each other by phone and we provide calmness for each other and if we have any questions, we ask each other”.

Two of the mothers in this study had similar experiences with the disease which had passed the surgical and treatment process. The difficulty of caring for these mother was a lot more than mother who were not sick.

Participant [14] expressed in this regard:” I myself had open heart surgery. At first, I could not bear that he had to do pen heart surgery too. I was extremely difficult. I can remember how much pain I had and how much hardship I endured. But then I could understand the feelings of my child after surgery. I knew what to do for him. Which food I should give to him and how to take care of him. Although it was hard, but I think now I can understand my child better than other mothers because I have had the experience of this surgery and for this, I could take care of him better”.

4. DISCUSSION

A total of 23 patients (25 interviews) participated in the study. 17 were mothers of children with congenital heart disease, three were fathers and three were nurses of cardiac surgical intensive care unit. The age range of participating mothers was 27-50 years (the average of 33.5 years). Interviewed mothers had children with congenital heart problems in different degrees and intensities and under treatment in different stages of disease. Wise to wait, improving living conditions, acceptance of limitations of sick child, empowering classes appeared by analyzing data.

The available scientific evidences about the importance of codes will be provided in this section. Although there was a small amount of qualitative article but we tried to review booth qualitative and quantitative articles.

4.1 Wise to Wait

The definitive diagnosis of the disease is very hard news for parents [24]. Parents of sick

children, especially chronic patients, face issues related to management of the child's disease in addition to facing the problem of transition to parental period [25]. The multiplicity of problems related to the treatment and care of sick children cause in them a high level of stress in them. Mothers in the present study faced a severe stress by observance of their sick child similar to Helgestone who confirms the high level of stress in mothers of children with diabetes in a quantitative study [24]. Also in numerous other studies, fear of losing the child after definitive diagnosis has been mentioned as the greatest and worst mental stress of the parents [26]. In this study, spiritual disquiet of mothers after the sickness of fathers was more evident. Due to the fact that mothers have an extremely deep emotional connection with their child in Iranian culture, the person who is most concerned about the disease of the child is mother and on the other hand mothers are considered as the main caregivers of children. The study of Magana in 2014 also stated that mothers have had the main role of taking care of the child in children with schizophrenia [27]. Participants in this study children despite mental stress resulting from child's disease, tried to use all available resources to provide optimal care of their children in order to provide a relatively normal life for the sick child and the family. They used every idea and method that came to their mind for maintaining the existence of themselves, their child and their family [28].

The child's illness not only puts the mother's life out of normal conditions but also the lives of the family members and sick children themselves [10]. In this study due to the harsh conditions of life of the mother, emotional support for the mother is essential for effective care for the child and the absence of this kind of support was completely evident in the life of the mother. As it has been emphasized in the study of Fonseca that improving the maternal mood of mother is extremely helpful in caring for the sick child [9]. Mothers in the study were trying to increase their tolerance using methods such as communicating with each other (mothers of children with similar diseases) and having patience on what had happened. According to a study in 2015 the amounts of emotional tolerance in mothers are different [14]. As mothers in our study were more anxious than others about some of the problems. Some of them despite passing over three or four years with pediatric patients and continuous conflict were still asking themselves why them?

Why their child? I was clear that they still had not accepted the conditions. Late acceptance of physical condition intellectual engagement with why and how my child got sick did lead to providing a quality care and these conditions not only did not satisfy the mother, but it also created feeling of guilt in mothers. But in the meantime, a large number of mothers decided to have patience, I a way that they always said we should be patient and they had this feeling not only in physical care of their child, but also in all aspects of life and this greatly reduced the burden of problems.

In this study, believing in patience and applying religious teachings in providing optimal care to children had a great influence. In a study in 2014 believing that what God wants rises to led to mental relief of mothers [29]. Among the participants in this study, Mothers who had stronger religious beliefs were more relaxed. Most of the mothers were raising their mental capacity and patience through praying and going to the mosque and participating in religious ceremonies, similar to many studies where patient's family expressed praying and going to church to be a relaxation method for them [14,30]. Some mothers act patiently against difficulties by adding patience and resistance pattern in their religion. For example, a mother in pointed out characters in Culture like Ms. Zeynab and modeled her biography. In Muslim rituals, Zeynab is a resistant and patient woman who was alongside of her family and was the nurse of her family. She endured many hardships during her life and mother noted her character a lot in their interview and considered her to be their role model.

Whaley and Wong also noted in confirmation of the results of the current study that Families that believe in religious philosophy, believe that problem is a way for having success and more faith [31]. All of the mothers in this study had the experience of patiently caring for their child in a way that they acted calm and with caution in all actions concerning the child, from the method of feeding them to type of behaviors they had against their child. They even acted patiently in evolving and gaining movement skills of the child. In the study of Zhang in 2014 which studied the adaptation strategies of parents of Chinese children awaiting liver transplantation, caring with caution has also been expressed as experiences of parents of these children (Zhang et al., 2014).

4.2 Improve Living Conditions

In this study, the mothers of these children faced with the challenge of lack of awareness and knowledge of how to care. They were trying to achieve necessary information for optimal care but a lot of their stress and concerns were related to lack of their knowledge of the disease process and its management. But they always used any ways they could in order to achieve care information. But sometimes they had to carry out the caring using trial and error which sometimes led to occurrence of physical symptoms for the child and would add to the concerns of the mother. Providing information about method of caring and treatment to parents and family members with a child with chronic diseases has been emphasized in the study of Moreira et al in 2013 similar to this study [21]. Parents being aware of child health, disease, treatment and prevention of complications will lead to improved health behaviors and method of caring for their child which all can be helpful in improvement of care of children with CHD [13].

Nurses play the most important role in providing knowledge necessary for care which is more highlighted in our country due to low number of nurses and lack of family nurse. In the study of DeMaso and Snel which has been carried out with aim of improving compatibility level of children undergoing surgery, training parents and making them aware of necessary caring for the child have always been emphasized. In this study, nurses made parents aware of the surgery and care before, during and after surgery to the extent that they introduced books related to the age of child to them [22]. But the camps where mothers of these children can experience their hours together and with each other can reduce maternal anxiety and makes them more aware of how to care. Also close contact of mothers with each other and care team has been emphasized in the study of Haskell and parents and families of child with heart disease have been mentioned as care partners [13]. In the context of the current study, conditions should be provided where parents are more involved in care and work process of their child during care so that the caring gets better and better. Unfortunately the children in Iran receive good care from nurses until they are hospitalized but they will be forgotten after the discharge and no one except the parents, follow-up the child's conditions. The care and treatment team do not have agent to refer patients after discharge and parents

often do not go to the hospital because of unawareness and lack of symptoms. Educational and follow-up programs at home are necessary for this group of parents and children. Similar to the study of Harvey which has emphasized the experiences explanation of mothers of children with congenital heart for disease support and educational programs to have more efficient care [32]. Training on methods of proper use of available resources, making mothers aware of treatment process and knowledge about disease, referring mothers to finance supporting centers for chronic patients, forming groups where mother of children with similar disease are gathered together and provide their experiences to each other are among things that nurses can do for mothers to do the caring with more quality. When mothers are alongside each other, they will empower each other in management of sick child compared to doing it by themselves. On the other hand, existence of nursing staff with awareness for empowering the mothers and teaching life skills [22] to them for controlling created situations are one of the main needs of mothers in Iran. Effective nursing interventions (Aarhun and Akerjordet, 2014) and the availability of nurses at all hours of the day, especially when the child is at home while experiencing bad conditions for doing necessary supports and creating the extend of on time caring for mothers for having proper behavior with the child and strengthening family bonds is a necessary. The study results show that remote nursing systems are extremely effective in creating relaxation and improving mental status of chronic patients and their families, reducing financial costs, solving the problems of long travels of children and their parents, reducing their referrals and improving their quality of life (Kamei, 2013).

Encouraging mothers in taking care of themselves while caring for sick child and stating that if they are healthy, then they can provide quality care for their child are among other issues that nurses must pay attention to in dealing with these mothers and the study results show that parents' health is extremely effective in physical and mental improvement of their sick child [24]. Providing conditions for coordination and cooperation of schools and kindergartens (by adding nurses with academic education) so that the children can spent some time with their peers is effective in peace of mind for mother and increased happiness and joy of the child which all lead to better results. These children have levels of anxiety, stress and depression higher

than healthy children [29]. So paying attention to their psychosocial health is a necessity [33].

Effective care from family members is possible by a careful planning and effective accompany of the mother which is capable of being realized if all of these are realized. One way of empowering is providing educational packages for children and families in the field of communication and teaching how to live with peers [34]. Based on evidences, detailed plans of education are helpful in patients to improve care and disease control. In addition to training to patient, training parents and those who care for the sick can also be effective in improving control and patient care [7].

In many cases mothers in this study had to change the existing situation in order to create peace in the lives of children based on available resources and possibilities to have optimizing and positive caring outcomes. Mothers participating in this study faced the hard task of matching working hours with caring for their sick child in a way that some of them had quit their jobs in order to take care of their sick child full time and if possibility of part-time work or work at home is provided to these mothers, it will help to increase the endorsement of caring difficulties and their spiritual strength and improved spiritual strength of mothers in difficult conditions of caring for child helps them to have a proper caring and based on the results of some studies, a job for mother leads to more independence, sense of empowerment, increased caring commitment and increased life expectancy [35].

But during the course of the sickness of the children's due to lack of supporting resources in our country, most of the mothers manage the condition of their child's disease with or without receiving any psychological or financial help which leads to reduced quality of life for mothers of these children [16] and to the same extent, there will be no proper and quality caring for child from the mother [36]. Mother during caring of children with congenital heart disease have always changed their living conditions in order to have the best type of care and as much as possible for the child. They are forced to accept many issues, difficulties of giving medicine to the child or excuse-makings of the child and they have used their special maternal innovations in some cases in order to adjust the conditions of life for their sick child. For example, the use of peers and establishment of good relationship with them for the care of children in school and buying toys

that require more intellectual activity rather than physical activity.

Accepting inability and implementation of dietary restrictions and activities restriction by the mothers were among the things that mothers did to provide effective care for these children. Although this step was achieved gradually over a long time, but mothers who reached this stage earlier and faster and accepted the conditions had better caring.

Empowering the child for doing his/her own things was among other things that mother had experienced in management of their sick child which not only led to creation of motivation and interest for the child in self-care, but in many cases led to more attention of child to self and balancing a lot of stubbornness and mothers did this without any special training and creatively. Results of studies show that Young patients suffering from chronic diseases will have better control over their disease by empowerment and take care of themselves more actively. Thus, empowerment of patients will improve their health promotion behaviors [37]. More efforts at achieving a faster recovery, increased knowledge, improving the quality of life of patients are among consequences of empowerment [38] which is quite consistent with our study.

Mothers in the study indirectly empowered their child by respecting him and caring about him and this was the key to success for this group of mothers in caring for their sick child.

In this study, mothers used experiences of others and their own at all stages of child's disease in order to provide a good care. Learning the experience of other mothers who had a child similar to their child during hospitalization and meeting other mothers of children as well as using their experience (mothers who have had the experience of similar illness) Was an important strategy that the majority of mothers had experienced.

On the other hand mothers have always tried to improve the care process by consulting with knowledgeable people, obtaining information and knowledge of key points of patient management and care. They used every opportunity to learn. Positive impact of informing Child Care Providers to improve quality of care and disease control is no secret. Based on evidences, detailed plans of education are helpful in patients to improve care

and disease control. In addition to training to patient, training parents and those who care for the sick can also be effective in improving control and patient care [39]. Proper understanding of parents about children's heart problems and risk behaviors can help the improvement of care for children with CHD a lot. Mothers of children with CHD believe that their biggest problems are related to their lack of knowledge of the child's future, treatment planning and treatment outcome [15]. In this regard, nurses must help mothers by providing educational merits based on the mother's needs in providing safe care for children and remember that empowering caregivers of children with chronic diseases is not merely knowledge transfer but rather change in behavior, skills training and knowledge must be taught together to parents. The effect of this empowerment leads to empowerment of parents in correct and informed decisions and playing an active role in planning and decision-making related to children.

5. CONCLUSION

The current study data showed that mothers to the extent of their ability to provide effective and quality care based on the capabilities and resources available when facing problems of taking care of their sick child and method of their application is different based on culture, mindset, method of caring and disease. But, their method of disease management and issues related to their child not only leads to deep understanding of their and their children's needs, but it also informs the nurses to improve the abilities of mothers and their caring level by implementation of care training programs based on their needs and priorities and providing better care form the mother improved the lives of children. Also effective steps can be taken for improvement of quality of life of this group of mothers and children by using administrative measures and implementation of support programs.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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